

FAMILY MODULE ONE: ABOUT AUTISM SPECTRUM DISORDERS

*Developed by the Indiana Resource Center for Autism
Indiana Institute on Disability and Community
Indiana's University Center for Excellence on Disabilities
Indiana University*

I. CHARACTERISTICS OF PERVASIVE DEVELOPMENTAL DISORDERS (PDD)

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; APA, 2000) identifies the characteristics necessary to receive a diagnosis of a Pervasive Developmental Disorder. Autism is one of five developmental disorders classified as a Pervasive Developmental Disorder (PDD). All of the disorders are referred to as syndromes. This means that diagnosis is based on a defined group of behaviors which combine to result in a disrupted pattern of development. The term “pervasive” was chosen for this group of disorders because people demonstrate difficulties in multiple, as opposed to specific, areas of development. Difficulties in one area of development (e.g., social) impact other areas of development (e.g., communication). The result is an extremely complex group of features and characteristics. An updated version of the diagnostic criteria determined by the American Psychiatric Association in the Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition—Text Revision (DSM-IV-TR) is maintained at <http://www.iidc.indiana.edu/irca/generalinfo/diagnosticcht.html>.

Your son or daughter has received a diagnosis that falls under the category of Pervasive Developmental Disorders. Again, there are five subtypes under this category. The three subtypes under this category that together are often called autism spectrum disorders are: Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. The other two subtypes under this category are Rett's Disorder and Childhood Disintegrative Disorder.

Rett's Disorder and Childhood Disintegrative Disorder have different patterns of development and challenges than autism spectrum disorders. There are enough similarities, especially in the areas of communication and social interaction characteristics, that all five types are considered Pervasive Developmental Disorders. This module focuses only on the three subtypes commonly referred to as autism spectrum disorders.

Autistic Disorder (or Autism): Characterized by difficulties in communication, social interaction and imaginative play, and the presence of restricted interests and activities prior to the age of 3. A child with autism develops both receptive and expressive communication in a different fashion. Frequently, there is a delay or a severe lack of development of spoken language. In a growing minority of children, language develops appropriately and then seems to stop suddenly before the age of 3. The higher functioning child with autism may develop elaborate language but have a hard time initiating and sustaining a conversation. Some children may repeat what they hear from other people, television, or videos. This is referred to as echolalia.

Your child with autism may appear uninterested in peers and may appear more comfortable in his/her “own world.” Play may consist of solitary activities not involving others. Play “routines” may be repeated over and over with little variation. There may be a lack of or unusual eye contact, limited facial expressions including a “social” smile, and delayed sharing and enjoyment with others (e.g., pointing to or bringing/showing objects of interest).

These children may engage in the same movement (e.g., hand flapping, rocking) repeatedly or may only play with certain toys or items. Often the items are not used in an appropriate fashion. For example, instead of rolling a truck on the ground, a child may spin the truck wheels. This is often called self-stimulation.

Asperger’s Disorder (or Asperger’s Syndrome): Individuals experience the same characteristics of autism, but according to the diagnostic criteria have no clinically significant delay in language. Measured intelligence is in the average to above average range. Frequently children show an almost obsessive interest(s) that is unusual in intensity and focus, and may make them appear to be a “little professor.” For example, your son or daughter may be intensely focused on trains, facts about dinosaurs, or maps.

Your child may be interested in having friends, but may not know how to interact with peers. Your child may not seem to understand the unwritten rules of friendship and how to “fit in.” There are significant problems understanding the thoughts and feelings of others, and regulating social interactions and emotions.

Pervasive Developmental Disorder Not Otherwise Specified (or PDD-NOS): This is the diagnostic label given when a child does not meet criteria for a specific diagnosis, but there are severe and pervasive difficulties in social and communication behaviors.

Autism is referred to as a spectrum disorder to signify differences among a group of people who share a common diagnosis. Even though individuals diagnosed with an autism spectrum disorder share a common set of behavioral

characteristics, no two individuals will be alike. Each can act very differently from another and have varying skills.

Although currently not part of the diagnostic criteria, the majority of people on the autism spectrum experience sensory processing difficulties or sensory sensitivities. Individuals with autism frequently perceive sensory information such as sounds, smells, textures, tastes, and sights differently. Your child may show an over (hyper) reaction or under (hypo) reaction to various sensory input. For example, certain sounds (e.g., fire alarms, vacuums, sirens) may be painful for the individual or particular smells (e.g., perfumes, potpourri) may be overly distracting. Various types of lighting (e.g., fluorescent) may be visually painful for the individual making it hard for them to focus on the task at hand. Some may only eat certain foods because of the texture or taste. And others may show no reaction to painful circumstances such as ear infections or burns.

There is still little awareness of the movement differences that affect many individuals on the autism spectrum. Your child may have difficulties in controlling a variety of movements such as starting, stopping, continuing, combining, and switching. This movement difference can affect many areas of functioning. Responding to requests, participating in group activities with others, and even getting to the bathroom on time may be affected by a movement difference. Often these movement difficulties are mislabeled as deliberate misbehavior. Visit the webs at <http://www.iidc.indiana.edu/irca/behavior/movementcloselook.html> for an IRCA article that describes how the body works as a dynamic system. Each part of this system needs to work in tandem in order for movement to occur. In individuals with autism, the system may be unbalanced leading to movement differences. Implications of these movement differences are discussed. Visit the web at <http://www.iidc.indiana.edu/irca/behavior/movementdif.html> for an IRCA article that further considers movement differences and provides examples of how certain behaviors can be interpreted in terms of functions or movement differences.

Many children on the autism spectrum experience difficulties in two other areas: theory of mind and executive functioning. Executive functioning refers to our ability to juggle or handle multiple tasks or activities. It is a term that generally is linked to difficulties in mental planning, working memory, inhibition, impulse control, and mental flexibility. Theory of Mind refers to the fact that the mind is comprised of beliefs, desires, emotions, perceptions and intentions. Children on the autism spectrum have difficulty understanding the beliefs, desires, emotions, perceptions and intentions of others. As a result, sometimes they are perceived as lacking empathy or being insensitive. On the other hand, not understanding the intentions of others may make individuals on the spectrum vulnerable to bullies and others who do not have their best intentions in mind. According to Howlin, Baron-Cohen, and Hadwin (1999), the implications of these theory of mind difficulties include the following:

- Insensitivity to the feelings of others;
- Not taking into account what other people know;
- Difficulty forming friendships because of lack of reciprocity;
- Not realizing when others are not interested in what one is saying;
- Taking all language literally;
- Not being able to predict what others will think about one's behavior;
- Inability to understand misunderstandings;
- Inability to deceive or understand deception;
- Not understanding the reasons behind the actions of others; and
- Difficulty with "unwritten rules" or social conventions.

Some children exhibit challenging behaviors. These behaviors may include self-injurious behavior (SIB), aggression, self-stimulation, refusal to follow directions, withdrawal, and others. Realize that these behaviors may be serving a real purpose for your son/daughter, or may be a reflection of other issues in your child's life. It will be important to involve professionals who understand how to assess behavior, and how to work collaboratively with others in establishing a behavioral intervention plan that is realistic within the context of the home and other settings. Other modules cover this topic more in depth.

Autism spectrum disorders can occur by themselves or in combination with other disabilities such as attention deficit hyperactivity disorder (ADHD), learning disabilities (LD), anxiety disorders, depression, obsessive compulsive disorders (OCD), blindness, deafness, epilepsy, and/or mental retardation (MR). A secondary diagnosis will influence the particular characteristics or behaviors an individual displays, and the type of interventions needed.

II. DIAGNOSIS AND ASSESSMENT

ASSESSMENT FOR THE PURPOSE OF DIAGNOSIS

When an individual is suspected of having an autism spectrum disorder, obtaining an accurate diagnosis can be a time consuming, costly and confusing process. An initial diagnosis can be made by a psychologist and/or medical doctor who has training and experience in understanding autism spectrum disorders and other developmental disabilities. Remember that there is no medical test for autism. While professionals can suggest, based on observation or a brief office visit, that your child may have an autism spectrum disorder, an accurate diagnosis requires an appropriate and thorough assessment and observation.

An accurate diagnosis is based on an observation of specific behavioral characteristics across a variety of environments/situations and a comprehensive history of early development. The behavioral characteristics typically used are

listed in the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association. .

The Indiana Resource Center for Autism recommends a multidisciplinary assessment that includes a psychologist and family members. Since communication is always affected to some degree, it is important to include a communication assessment from a certified speech language pathologist. If the individual seems to be exhibiting sensory processing difficulties, it would be appropriate to have an assessment performed by a qualified professional. Often times, occupational therapists have the necessary training to assess individuals for sensory processing difficulties. Medical personnel, including neurologists, psychiatrists and pediatricians should be involved when there are issues related to medication and to assess for potential neurological, genetic or physical difficulties (e.g., seizures, brain lesions, Fragile X, allergies, digestive system problems). If the child is in a school program, an educator should be involved in the assessment to address a child's performance in the school curriculum, and to determine additional educational support needs. Other team members who might be involved include social workers, physical therapists, audiologists, and other health professionals.

If you are seeking a diagnosis and/or assessment for an individual of school age, including ages 3 through 5, contact your local school district for information. School districts employ psychologists and other professionals who can assess school-age children to determine if they meet eligibility criteria for an autism spectrum disorder. If your child is between the ages of 3 to 21, an educational assessment with a team of qualified professionals will be needed to determine eligibility for special education and related services. A "medical diagnosis" from a physician does not necessarily qualify an individual for educational services. School Psychologists refer to Article 7, Title 511, of the Indiana State Board of Education Special Education Rules when making a diagnosis. Article 7 stipulates the assessment process and procedures required to determine eligibility for special education services as a student with an autism spectrum disorder. The school's case conference committee (which includes the family) is to decide on a student's eligibility for services under the category of Autism Spectrum Disorders based on information obtained from the required evaluation procedures. A copy of eligibility requirements from Article 7 is included on our website at <http://www.iidc.indiana.edu/irca/generalinfo/article7.html>. Evaluations conducted through the school district are conducted at no cost to parents.

Remember the following:

- There is a great deal of subjectivity involved in making the diagnosis. In truth, one of the greatest variables is actually the clinical background of those who are conducting the assessment.

- Checklists provide a mechanism to analyze characteristics, however, these should be done along with natural observation across settings (home, classroom, playground, etc.). And the evaluator should have examples to justify marking a specific characteristic.
- Standardized assessments and curriculum based assessment can also be used. Perhaps the most obvious examples of curriculum-based assessment in Indiana are the achievement of state standards or IEP goals.

If a family or agency wants a private or second evaluation, there are individuals and agencies located across Indiana who have experience diagnosing and assessing autism spectrum disorders. A list of these professionals and agencies is on our website at <http://www.iidc.indiana.edu/irca/fdiagnosis.html>. Some of the professionals on this list also may be able to provide assistance with medications, educational programming, speech therapy, behavioral support, and/or with counseling or psychiatric services. The Indiana Resource Center for Autism does not recommend a specific organization or person. When contacting those listed, discuss the cost of the evaluation, the testing procedures and assessment instruments used, and the type of follow-up report. A thorough assessment should allow the examiner to gather sufficient information about areas of strength and need, educate the family regarding the diagnosis, and provide information that logically leads to programming recommendations. When pursuing a private evaluation, contact your insurance company to determine how much and what portions of the assessment will be covered.

III. INCIDENCE

In the last 10 years, the estimated prevalence of autism spectrum disorders has gone from 2-5 in 10,000 to 1 in 166 to 1 in 150 according to the Centers for Disease Control. Prevalence studies are underway in various portions of the United States and abroad. Unfortunately, cost and time commitments have prevented more wide spread studies. Visit our website at <http://www.iidc.indiana.edu/irca/generalinfo/increasing.html> for an article that discusses the increasing incidence in Indiana. You can also visit the Centers for Disease Control and Prevention Autism Information Center at <http://www.cdc.gov/ncbddd/autism/index.htm> for further information on incidence rates.

IV. POSSIBLE CAUSES

There is no single known cause for autism spectrum disorders. There are many theories about potential causes. As research continues, it appears there are multiple factors involved. Current thinking and/or research points to the following possibilities: viral infections, an adverse reaction to vaccinations, an adverse

reaction to thimerosal (a mercury containing preservative in some vaccines), pollutant exposure during pregnancy, metabolic disorders, enzyme deficiencies, birth complications, and/or various defects in body chemistry and/or the immune system. Research is divided and inconclusive in a number of these areas.

There appears to be a strong genetic component to the disorder. ASD tends to run in families with siblings having a 10-20 percent chance of being identified (American Academy of Neurology-AAN). Identical twins have a 60-71 percent chance of both being diagnosed with an autism spectrum disorder. Multiple genes have been implicated as possible causes of the characteristics associated with autism (chromosome 7, 15, and 17). More research is being conducted in this area.

Regardless of the cause, we know that autism spectrum disorders are neurologically-based, and not emotional or behavioral disorders. Based on Cat Scans and MRI's, there appears to be a variation in brain functioning. For example, the area of the brain that controls social functioning may be different from child to child. The hypothalamus, frontal lobe, cerebellum, and brain stem have all been cited in the literature. Most important, parents do not cause their child(ren) to have autism.

III. DISCLOSURE OF THE DIAGNOSIS: WHAT DO OTHERS NEED TO KNOW?

At some point, it may be important to help your child understand their disability. While we understand that this is an individual decision, withholding the information from a child as they age may lead to confusion as they realize their differences. On the IRCA website at <http://www.iidc.indiana.edu/irca/generalinfo/getstarted.html> is an article on explaining ASD to your son or daughter. At the end of this article, other resources are listed to help with this process.

In terms of telling other family members, consider your needs, and your child's needs first. In almost all circumstances, you should be honest and forthright. Provide reading materials, videos or other resources to help them learn more about the disability and issues related to the disability (e.g., medical conditions, behavior, communication, social skills development). Often family members will be uncomfortable as a result of uncertainty. They may be uncertain on how to act, what to say, how to interact with you and your child, or what is expected of them. Once again, be open and let family members know what you consider to be appropriate (e.g., language, interactions) and what you expect from them.

In addition to materials on autism spectrum disorders that the IRCA has available, The Center for Disability Information and Referral (CeDIR) at the Indiana Institute on Disability and Community at Indiana University has many

specialized books and videos. The collection of materials at CeDIR contains information related to all disabilities including autism spectrum disorders. These materials are available for loan, to anyone in Indiana, free of charge. You can call CeDIR directly toll free: 800-437-7924 to arrange to borrow materials. You can also access their collection at: www.iucan.iu.edu. The IRCA has a many bibliographies on a variety topics related to autism spectrum disorders as well as an extensive listing on videos that may help you in selecting materials that are relevant to your needs. Check the IRCA web site and click on Library Collections www.iidc.indiana.edu/irca/books.html for a listing of books by topic or for a listing of DVDs/videos visit the website at www.iidc.indiana.edu/irca/fvideo.html .

Siblings will also need information. Each situation is different. However, it may be helpful to provide general information about autism spectrum disorders and then specific information about their sibling on the autism spectrum. Information should be age appropriate. Don't expect the sibling to be an immediate advocate or always be understanding. Give them time to adjust and make their own decisions. Be available for questions about the future and their potential role. Most important, make time for siblings so they feel important and not cheated by their brother/sister on the autism spectrum. Some siblings may require counseling or the opportunity to talk to an outsider to help them cope. For more information, visit the website at <http://www.iidc.indiana.edu/irca/family/siblingbib.html> and at <http://www.iidc.indiana.edu/irca/family/SibPerspect.html>.

There are two sides to the question of whether to disclose and to whom outside of the family. What might be the benefits and drawbacks of disclosure to others? This can be a difficult decision and one that is an individual and family decision. Do you choose not to disclose and hope your child's behavior will not isolate him or her from peers? You may fear that telling peers at school and others in the community might cause them to avoid your child or worse target your child for further teasing. Most likely peers and others in the community know there is something different about our son or daughter, but they lack accurate information on the reason. Sometimes lacking information can also lead to others avoiding and/or teasing your child because people make wrong assumptions about why your child is behaving "differently".

Unfortunately, for one reason or the other, there will be people who are intentionally cruel. You can't expect these people to be interested and understanding about your child even when given information. Fortunately the majority of peers and others appreciate knowing about your child's disability and learning what makes him or her unique as well as how he or she is like other children.

If you do decide to disclose, it helps to plan and prepare ahead. When choosing to disclose to classmates it is important to involve your child's teacher and possibly other school staff. Many parents and teachers work together to plan a

presentation for the classroom. You, your child's teacher, other school staff and/or your child may be involved in the presentation. You do need to consider what role your child will play in the process. Will he or she want to share certain things? Will your child be present for the presentation or even help? It may be that you prefer to not have your child present for the program with the classmates. This decision may vary depending on your child's age and his or her desire to be involved.

It is likely you have experienced an unfortunate episode in public, when your child's behavior has become disruptive or destructive. Even with planning and preparation situations may get too frustrating or overwhelming for him or her. As a result of your child's behavior bystanders may stare and gawk or worse make critical or insulting comments. Many families find that they like to carry small cards to hand out when this happens. The card, often the size of a business card, contains facts and information which briefly states their child's diagnosis, an explanation about the challenging behavior and where to find more information about autism spectrum disorders. See the web site for the Autism Society of America at https://secure2.convio.net/asa/site/Ecommerce?store_id=2001&JServSessionIdr010=b4s8rpsku3.app27a for information on purchasing these cards or other awareness information.

Now use the information above to think about your child:

1. Describe communication challenges experienced by your child.

2. Describe social deficits experienced by your child.

3. Describe sensory processing challenges experienced by your child.

4. How do difficulties in theory of mind and executive functioning impact your child?

5. Now that we have talked about challenges, let's discuss strengths. What does your child enjoy and do well in? What are his/her strengths and talents?

6. How does your child learn best? What works for your child?

7. What is important for your child to be able to do to participate more fully as a family member?

For more information about the Indiana Resource Center for Autism, visit our website at www.iidc.indiana.edu/irca or email Dr. Cathy Pratt at prattc@indiana.edu.

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The Indiana Resource Center for Autism (IRCA) is one of seven centers located at the Indiana Institute on Disability and Community at Indiana University, Bloomington. The work of the Indiana Institute encompasses the entire life span, from birth through older adulthood, and addresses topical areas that include:

- ◆ Early intervention and education;
- ◆ School improvement and inclusion;
- ◆ Transition, employment, and careers;
- ◆ Aging issues;
- ◆ Autism spectrum disorders;
- ◆ Disability information and referral;
- ◆ Planning and policy studies; and
- ◆ Individual and family perspectives.

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For more information, contact: The Indiana Resource Center for Autism, Indiana Institute on Disability and Community, Indiana University, 2853 East Tenth Street, Bloomington, IN 47408-2696, call (812) 855-6508, or visit our web site at www.iidc.indiana.edu/irca.

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These materials are available in alternative formats upon request.